ORIGINAL ARTICLE

REVISTA ENFERMAGEM ATUAL IN DERME

WELCOME HOME: DIFFICULTIES OF CAREGIVERS OF PREMATURE INFANTS AFTER HOSPITAL DISCHARGE

BIENVENIDO A CASA: DIFICULTADES DE LOS CUIDADORES DE BEBÉS PREMATUROS DESPUÉS DEL ALTA DEL HOSPITAL

BEM-VINDO AO LAR: DIFICULDADES DOS CUIDADORES DE BEBÊS NASCIDOS PREMATURAMENTE APÓS A ALTA HOSPITALAR

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ABSTRACT
Objective: To identify the difficulties of caregivers after hospital discharge from the Neonatal ICU. **Methodology**: Research with a quantitative approach, transversal type of descriptive and exploratory character. Developed in the follow-up/Follow-up clinic of a tertiary hospital in Rio de Janeiro. The research volunteers were parents or caregivers of preterm infants with a gestational age of less than 37 weeks and who had at least fifteen days of hospitalization. Data were collected through an interview during first follow-up appointment, carried out after one week of discharge. Data analysis was performed using descriptive statistics. **Results**: 15 caregivers were included in the study. Among the guidelines that were not received, warning signs (70.6%), bottle cleaning (52.9%) and pacifier use (52.9%) stand out. When relating the length of stay in the NICU with the guidelines received, we see that caregivers whose newborns spend less time in the NICU end up having less guidance on temperature care, hygiene care and warning signs. **Conclusion**: The results presented here showed that the arrival of the family at home with the baby represents a break with the world of hospitalization and generates experiences specific to the home context.
Keywords: Patient Discharge; Premature Infants; Neonatal Intensive Care Unit

RESUMEN
Objetivo: Identificar las dificultades de los cuidadores después del alta hospitalaria de la UTI Neonatal. **Metodología:** Investigación con enfoque cuantitativo, de tipo transversal de carácter descriptivo y exploratorio. Desarrollado en el ambulatorio de seguimiento/seguimiento de un hospital de tercer nivel en Río de Janeiro. Los voluntarios de la investigación fueron los padres o cuidadores de recién nacidos con edad gestacional menor de 37 semanas y que tuvieran un tiempo mínimo de quince días de internación del niño en la UCIN. Los datos fueron recolectados a través de una entrevista en la primera visita de seguimiento del RN, realizada después de una semana del alta. El análisis de los datos se realizó mediante estadística descriptiva. **Resultados:** Quince cuidadores fueron incluidos en el estudio. Entre las orientaciones que no fueron recibidas, se destacan las señales de advertencia (70,6%), limpieza del biberón (52,9%) y uso del chupete (52,9%). Al relacionar el tiempo de permanencia en la UCIN con las orientaciones recibidas, vemos que los cuidadores en los que el RN permanece menos tiempo en la UCIN son los que terminan teniendo menos orientaciones sobre cuidados de temperatura, cuidados de higiene y signos de alarma. **Conclusión:** Los resultados aquí presentados mostraron que la llegada de la familia a casa con el bebé representa una ruptura con el mundo de la hospitalización y genera vivencias del contexto domiciliario.
Palabras clave: Alta del Paciente; Bebés Prematuros; Unidad de Cuidado Intensivo Neonatal.

RESUMO
Objetivo: Identificar as dificuldades dos cuidadores após a alta hospitalar da UTI Neonatal. **Metodologia:** Pesquisa de abordagem quantitativa, tipo transversal de caráter descritivo e exploratório. Desenvolvido no ambulatório de seguimento/ Follow-up de um hospital terciário no Rio de Janeiro. Os voluntários da pesquisa foram os pais ou cuidadores de recém-nascidos com idade gestacional menor que 37 semanas e que tiveram o tempo mínimo de quinze dias de internação do filho na UTIN. Os dados foram coletados através de uma entrevista na primeira consulta do RN no follow-up, realizada após uma semana de alta. A análise dos dados foi feita por meio de estatística descritiva. **Resultados:** Foram incluídos no estudo 15 cuidadores. Dentre as orientações que não foram recebidas destaca-se os sinais de alerta (70,6%), Limpeza da mamadeira (52,9%) e uso da chupeta (52,9%). Ao relacionar o tempo de permanência na UTIN com as orientações recebidas vemos que os cuidadores em que o RN permanece por menor tempo na UTIN são os que acabam tendo menos orientações sobre os cuidados com a temperatura, cuidados com higiene e sinais de alerta. **Conclusão:** Os resultados aqui apresentados mostraram que a chegada da família ao domicílio com o bebê, representa o rompimento com o mundo da internação e gera experiências próprias do contexto domiciliar.
Palavras-chave: Alta do Paciente; Recém-Nascido Prematuro; Unidades de Terapia Intensiva Neonatal.

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INTRODUCTION

Hospitalization in the Neonatal Intensive Care Unit (NICU) is considered a potential measure in reducing infant mortality, especially in the neonatal component. For parents, the need for hospitalization of the child influences feelings of anguish, fear and helplessness in the face of the possibility of the baby's death. In addition, the long period of hospitalization negatively affects the strengthening of the mother-child bond and the development of the mother's skills for the care of premature infants[1,2].

According to the authors[3], for the family to be able to continue the care received by the newborns in the environment outside the neonatal unit, that is, to train them, the development of discharge planning is necessary. This aims to develop the ability of parents in care in order to avoid readmissions, reduce the family's stress level and identify community resources available for follow-up after hospital discharge. However, mothers often become responsible for the home care of these babies without being properly prepared[2].

The literature emphasizes the importance of preparing mothers for hospital discharge, throughout the baby's hospitalization, which leads to reduced anxiety, increased maternal self-confidence in home care and improvement in the child's home adaptation[4].

Planned hospital discharge, followed by a care plan, is part of a complex process that must involve, among others, the nursing team, which is incorporated into the process as vigilant, humanized and individualized care. However, it is observed that some professionals still do not view the activity as something essential in promoting the health of preterm newborns[4].

The aim of the present study is to survey the difficulties of caregivers of premature newborns after hospital discharge.

METHODOLOGY

It is a research with a quantitative, transversal, descriptive and exploratory approach.

The study was carried out at the follow-up clinic of a Federal Hospital in Rio de Janeiro, in the first medical appointment after discharge, with the objective of monitoring babies at risk from the NICUs and rooming-in.

The routine of consultations in the sector is carried out for children up to 6 months monthly, from 6 months to 1 year, bimonthly. From 1 year to 2 years, quarterly. From 2 to 4 years, every six months and from 5 years, annually. Most with follow-up up to 8 years.

Parents or caregivers of newborns with a gestational age of less than 37 weeks without a diagnosis of malformation or genetic syndrome and who had a minimum time of 15 days of hospitalization in the NICU were included. This inclusion criterion was chosen because it is believed that it is the minimum time necessary for parents to have the possibility of contacting a significant number of team professionals and also adapting to the routines of the sector and the child's hospitalization situation. in the NICU.

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Data collection took place through an interview with parents or caregivers. The interview had a guiding question (How was the hospital discharge and your arrival at home for you?) and, additionally, closed questions were asked. Both the guiding question and the data collection instrument with the questions were prepared by the authors. This collection took place for six months. At this stage, a Informed Consent Form was requested from parents and/or caregivers. The variables analyzed were: mother's job, number of children, maternal support, information about breastfeeding, preparation of supplementary food, use of pacifiers, positioning, care with temperature and hygiene, warning signs.

Data analysis was performed using descriptive statistics and the Mann-Whitney test.

The study is part of a larger project, approved by the Research Ethics Committee of the institution under number 3.098.916 CAEE 04636818.9.0000.5269. All those responsible (parents) for the participants signed an informed consent form. There was no case of refusal by any of the parents for the research.

RESULTS

Seventeen preterm infants participated in this research (presence of a pair of twins in the sample). The mean gestational age at birth was 31 weeks and 5 days.

The weight at discharge in sample was on average 2,548 grams, so we observed that the average of preterm infants in the research is well above the standards recommended by the Kangaroo method policy, which is 1600g[5]. It is worth mentioning that the Intermediate Care Unit (UCINCa) was not collected and could be closed for constructions, so the weight of 2000g was defined as standard of discharge (according to institutional protocol).

The length of hospitalization that characterizes this population was expressed in median of 40 days, a minimum of 17 days and a maximum of 110 days. The characterization data of the preterm infants in the study are shown in table 1.

Only one preterm infant had bronchopulmonary dysplasia and therefore there was no statistical significance before this study.

Table1 - Characterization of preterm ifants

Study variables	**N= 17**	
	Mean	Standard desviation

Gestational age of birth	31.5	2.8
Gestational age at discharge	38.0	2.1
Birthweight	1726.8	718.8
Weght at discharge	2548.4	530.1
Weight at first follow-up visit	2804.1	550.5
	mediana	Min – Max
Lenght of hospitalization	40.0	17 - 110

Source: prepared by the authors

With regard to maternal characteristics, 52.9% of mothers have at least completed high school and 64.7% of them do not work. The number of residents per house averages 4 people (SD ± 1.1)

The families in the study had a household income of less than thousand real (the unity of currency in Brazil) up to a maximum of three times this value, with only 11.8% of families receiving less than thousand real.

According to the study, 64.7% of mothers don't have a job, which contributes to the total dedication of the mother to the preterm infant that demands greater attention.

In our study, a relatively large percentage (82.4%) reported not having support at home with baby care. However, when they receive support, 58.8% of grandparents are the most mentioned. The father appears with 11.8% of the answers.

When they asked whether or not they received guidance on essential items in the care of preterm infants when they arrived at home, 100% answered yes regarding guidance on breastfeeding (Table 2). This is probably because the study institution is a Baby Friendly Hospital, and as such, it develops many educational activities about breastfeeding from prenatal care to follow-up after hospital discharge.

Temperature measurement is an item that draws attention in this study, because is a simple, fundamental task in care and performed daily by the nurse team, every 6 hours (in cases of normothermic babies). According to the mothers' answers, 47.1% of them do not receive guidance on how to measure the baby's temperature.

A very high percentage (70.6%) was observed in the response related to warning signs. Mothers report having difficulties in identifying which signs they need to observe that denote that the baby may need emergency care (Table 2).

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Table 2 - Caregivers' response to guidance received at discharge

Guidance	Yes		No	
	n	%	n	%
Breastfeeding	17	100	0	0
Baby Hygiene	14	82,4	3	17,6
Bottle feeding preparation	13	76,5	4	23,5
Newborn positioning	12	70,6	5	29,4
Newborn temperature	9	52,9	8	47,1
Pacifier use	8	47,1	9	52,9
Bottle cleaning	8	47,1	9	52,9
Baby warning signs	5	29,4	12	70,6

Source: prepared by the authors

When performing the Mann-Whitney statistical test, we correlated the length of stay in the Neonatal ICU with the guidelines for hospital discharge. The Breastfeeding item was not relevant for this comparison since 100% of the mothers received this orientation.

It was observed that mothers whose preterm infants were hospitalized for longer reported receiving more guidance on preparing complementary feeding and cleaning the bottle (Table 3). This probably occurred because the longer hospital stay is a risk for not exclusive breastfeeding or weaning, so the use of complementary feeding is necessary[6,7]. When this occurs, guidance on such matters is given at discharge.

In the present study, draw attention to the fact that mothers whose preterm infants remained hospitalized for a longer period reported not having received any guidance on positioning the baby at home (Table 3).

Care with temperature, care with hygiene and warning signs showed that caregivers in which the preterm infants remains for a shorter time in the NICU are the ones who end up having less guidance on these matters that are essential for a safe arrival at home. A factor that contributes to this data is the time to prepare for discharge, since this often occurs very close to the newborn's discharge from the hospital. As a result, the family receives a large amount of information quickly, and an effective discharge is not performed.

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Table 3 - Correlation between length of stay and guidance at discharge

		Lenght of stay			
		Median	Mínimum	Máximum	P
Bottle feeding preparation	Não	31,0	17	110	0,64
	Sim	40,0	17	82	
Bottle cleaning	Não	34,0	17	82	0,75
	Sim	52,5	17	110	
Pacifier use	Não	44,0	17	110	0,68
	Sim	37,0	17	82	
Newborn positioning	Não	**44,0**	34	110	0,48
	Sim	37,0	17	82	
Newborn temperture	Não	**37,0**	17	110	0,26
	Sim	59,0	20	82	
Baby hygiene	Não	34,0	20	34	0,28
	Sim	45,0	17	110	
Baby warning signs	Não	**37,0**	17	110	0,52
	Sim	61,0	17	82	

Mann-Whitney test
Source: prepared by the authors

DISCUSSION

The institution where the present study was carried out stands out for being a reference for fetal risk and for having advanced medicine in the care of preterm infants newborns. However, during the period of data collection, there was a reduction in demand due to constructions in the unit and the fact that there were beds with technology-dependent children in the long time, making it difficult to admit preterm infants. In addition, the institution receives many pregnant women with prenatal diagnosis of malformations and syndromes that are not study inclusion criteria, contributing to the low research sample.

According to data from Information System on Live Births (SINASC) and the Mortality Information System, which aimed to assess the interaction between age and maternal schooling in neonatal mortality, despite the drop in neonatal mortality at national and global levels, the children of mothers with less than four years of schooling had a higher chance of neonatal death when compared to children of mothers with at least four years of schooling[8,9].

The study carried out by authors[10], shows that the transformations in neonatal mortality in the State of Rio de Janeiro followed with social inequality, showing a reduction only for women with intermediate and advanced education. By relating this study to our presented data, we see

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that more than half of the mothers have an advanced level of education, which takes these babies out of the vulnerability group for neonatal death.

According to author[11], the working mother assumes a triple working day, as a mother, wife and professional, and this creates a situation of conflict in adapting to her new role. The author also points out that the return to work contributes to the early introduction of food in the baby's life. In our study, we observed a high percentage of mothers who do not work, which is a factor that can be seen as positive in the care of the babies and especially in the maintenance of breastfeeding.

The high percentage of mothers who do not have home help in caring for the baby is worrying, since it is known that this support helps to minimize maternal difficulties in the face of the need for the baby and parents to adapt to the new environment.

According to the authors[12], despite the feelings of fear and insecurity experienced by the mother in performing some basic care with the preterm infant, the partner's help in sharing care at home contributes to maternal security. in baby care.

The authors[13] observed that baby bath is a question most frequently mentioned by mothers in their study. According to the authors, they are afraid of causing physical damage to the preterm infant because of their physical structure, which is apparently fragile. The authors also mention that the most frequent fears mentioned during the baby bath are the risk of falling and of water entering the ear canal.

However, in our study we observed that the bath was a well-crafted item. The nursing team seeks to guide them as soon as they show the will to do so.

The Brazilian Society of Pediatrics[14] brings in its manual that parents, in their preparation for discharge, should be instructed to identify warning signs and symptoms for the search for emergency care, such as weak crying or moaning, hypoactivity, excessive crying or irritability. severe, color change (cyanosis or pallor), poor sucking or refusal to eat, frequent regurgitation or vomiting, difficulty breathing, tremors or convulsions, abdominal distention, and hypothermia or hyperthermia. In our study, mothers reported difficulties regarding warning signs.

According to Department of Health in Brazil[5], inside the NICU, the newborn's postural care is a factor that enhances the quality of care for this clientele by collaborating in the regulation of the baby's physiological functions and thus reducing energy expenditure, providing a balance in the health.

this the responsibility of the entire multidisciplinary team to provide postural care in the NICU, however, in current articles, the most cited professionals are Physiotherapists and Nurses. The authors[15] postulate that physiotherapy professionals help in the recovery of respiratory and motor function, in addition to correct positioning in bed, in order to perpetuate the results of the therapy. However, nursing is

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the one that has a longer time acting in the care of the preterm infants, influencing the assistance to the positioning[16]. Therefore we saw that this orientation is part of a discharge plan that starts with the education in family health, starting from the multiprofessional team.

The recommendations for positioning the child at home according to the American Academy of Pediatrics[17], is that infants are placed to sleep in the supine position with firm surfaces, in the parents' room and in their own bed/crib in order to avoid sudden death and provide adequate sleep, peaceful and safe. Therefore, the mothers' reports of difficulties with regard to the positioning of the preterm infants may be a consequence of being discharged from the hospital without a plan of standard guidelines, being done in different ways[18].

The training of the mother directed to the home care of preterm infants is necessary throughout the period of hospitalization, thus reinforcing their skills, making them overcome fears and insecurities with the support of health professionals within the NICU and thus favoring the mother bond and son[19]. The authors[20] observed in their study that some professionals create a reductionist and technicist posture, directed only to the treatment of pathologies presented by NBs, not involving the family in the care.

We conclude that caregivers had difficulties with the care of babies after hospital discharge in several aspects, especially with warning signs.

FINAL CONSIDERATIONS

The main limitation of our study refers to the small sample size due to the specificity of the inclusion criteria and the short data collection time. Due to this factor the study will continue its search for more concrete and detailed results.

The health team must keep in mind the importance of a clear dialogue with these users who require more care, as a way of enabling them to have all the information they want and that this exchange of information makes it possible for the moment of arrival at home to be experienced. in a more peaceful way.

It is known about the difficulties of the on-duty teams of neonatal units and the need, at times, for an accelerated discharge due to the demand for beds. However, the experience of hospitalization and preparation for discharge is a unique event that will mark parents lives and, therefore, must be treated within this perspective.

It takes an effort from the entire team to raise awareness about how mothers and family members need knowledge and information. The time to welcome and inform mothers and family members cannot depend on the number of tasks that the health team has to perform. The importance of these tasks must be equated with the other procedures that do not fail to be performed because they are considered “vital”.

The high investment made in the initial care of a preterm newborn cannot be put at risk when it is considered that he no longer needs the technological care that exists in the hospital. It is

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necessary to ensure that even at home this baby is being properly cared for by its mother and family members.

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REFERENCES

1.Souza NL, Pinheiro-Fernandes AC, Clara-Costa IC, Cruz--Enders B, Carvalho JB, Silva ML. Domestic maternal experience with preterm newborn children. Rev Salud Pública. 2010;12(3):356-67

2. Siqueira, MBC, Dias MAB. A percepção materna sobre vivência e aprendizado de cuidado de um bebê prematuro. Epidemiol. serv. saúde. 2011 mar.; 20(1): 27-36.

3.Schmidt KT, Terassi M, Marcon SS, Higarashi IH. et al. Práticas da equipe de enfermagem no processo de alta do bebê pré-termo. Rev. Bras. Enferm, 2013; nov-dez; 66(6): 833-9.

4. Silva MCM, Sousa RMC, Padilha KG. Destino do paciente após alta da unidade de terapia intensiva: unidade de internação ou intermediária? Rev. Latino-Am. Enfermagem. 2010 mar./abr.; 18(2):224-32.

5. Ministério da Saúde (BR). Atenção humanizada ao recém-nascido de baixo peso: método canguru. Brasília (DF): Ministério da Saúde; 2002.

6. Balaminut T, Sousa MI, Gomes ALM, Christoffel MM, Leite AM, Scochi CGS. Aleitamento materno em prematuros egressos de hospitais amigos da criança do sudeste brasileiro. Rev. Eletr. Enf. 2018;20:v20a22. doi: 10.5216/ree.v20.50963.

7. Briere CE, McGrath J, Cong X, Cusson R. An integrative review of factors that influence breastfeeding duration for premature infants after NICU hospitalization. J Obstet Gynecol Neonatal Nurs [Internet]. 2014 [acesso em: 06 nov. 2019]; 43(3):272-81. Disponível em: https://doi.org/10.1111/1552-6909.12297.

8. Nascer no Brasil. Inquerito nacional sobre parto e nascimento (2011 a 2012). [Acesso em 2020 fev 18.] Disponivel em : https://nascernobrasil.ensp.fiocruz.br/?us_portfolio=nascer-no-brasil.

9. Brasil. Ministério da Saúde. Portal da Saúde: SINASC. 2017[site da Internet] [acesso em 2020 fev 18]. Disponível em: http://tabnet.datasus.gov.br/cgi/deftohtm.exe?sinasc/cnv/nvuf.def

10. Fonseca SC, Flores PVG, Camargo Jr KR, Pinheiro RS, Coeli CM. Escolaridade e idade materna: desigualdades no óbito neonatal. Rev Saude Publica. 2017; 51:94.

11. Medeiros, IY. Amamentação em mulheres que trabalham: não trabalho no trabalho. Dissertação (Mestrado em Saúde Pública). São Paulo: Universidade de São Paulo-Faculdade de Saúde Pública, 2006; p.161.

12. Couto FF, Praça NS. Recém-nascido prematuro: suporte materno domiciliar para o cuidado. Rev Bras Enferm. 2012; 65(1):19-26.

13. Rocha GMN, Feitosa MR, Carvalho REFL, Dodt RCM, Queiroz MVO, Correio EMCC. Dúvidas maternas na alta hospitalar do recém-nascido. Revista Univap, 2019; 25 (49):93-103.

14. Sociedade Brasileira de Pediatria. Prevenção da prematuridade: uma intervenção da gestão e da assistência. Documento Científico. Departamento Científico de Neonatologia; 2017.

15. Liberali J, Davidson J, Santos AMN. Disponibilidade de assistência fisioterapêutica em unidades de terapia intensiva neonatal na cidade de São Paulo. Rev Bras Ter Intensiva. 2014;26 (1):57-64.

16 Xavier SO, Nascimento MAL, Badolati MEM, Paiva MB, Camargo FCM. Estratégias de posicionamento do recém-nascido prematuro: reflexões para o cuidado de enfermagem

neonatal. Rev. enferm. UERJ, 2012; 20(esp.2): 814-8.

17. American Academy of Pediatrics - AAP. SIDS and Other Sleep-Related Infant Deaths: Expansion of Recommendations for a Safe Infant Sleeping Environment. Pediatrics. 2011;128(5): 1-27.

18.Goldberg N, Rodriguez-Prado Y, Tillery R, Chua C. Sudden Infant Death Syndrome: A Review. Pediatr Ann. 2018 Mar 1;47(3):e118-e123. doi: 10.3928/19382359-20180221-03. PMID: 29538785.

19. Santos, LM, Silva LS, Santana RCB, Santos VEP. Vivências paternas durante a hospitalização do recém-nascido prematuro na Unidade de Terapia Intensiva Neonatal. Revista Brasileira de Enfermagem, 2012; 65(5):788-794.

20. Costa MCG, Arantes MQ, Brito MDC. A UTI Neonatal sob a ótica das mães. Rev. Eletr. Enf. [Internet] 2010; 12 (4): 698-704. Disponível em: http://www.fen.ufg.br/revista/v12/n4/v12n4a15.htm.

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